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HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

Ottawa

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Elizabeth May

Member of Parliament / Député(e)
Saanich — Gulf Islands

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The Honourable Jean-Yves Duclos
Minister of Health
House of Commons
Ottawa, Ontario
K1A 0A6

January 16, 2023

Dear Minister Duclos,

I am writing to you to request funding of \$10 million for the ALS Society of British Columbia to support the second phase of their initiative, *Project Hope*, which seeks to create a world class ALS Centre at the University of British Columbia.

ALS is a serious health condition that affects thousands of Canadians across the country, with nearly 1,000 people dying from the disease each year. It is a debilitating illness that becomes progressively more impactful on the daily life of those afflicted and the average prognosis is two to five years, so rapid action to address the disease is crucial. There are many promising ALS therapies currently in late stage clinical trials, but the treatment infrastructure that currently exists in BC is inadequate and further support for ALS research is urgently needed to help Canadians already struggling with the disease and the search for an eventual cure.

Project Hope's goal of creating a world class ALS Centre at UBC, including an ALS Professorship in Research, would allow for clinical trials to be conducted directly in BC. This will provide a combination of both research and quality clinical care that is currently not available in the province, making it so patients suffering from the increasingly severe mobility impacts of the disease would not have to travel great distances if they want to receive treatment.

The ALS Society of BC has already done exemplary work, raising over \$5.3 million to support the first phase of Project Hope. This fundraising goal was partially support by the provincial government with a contribution of \$3 million, but the remaining \$2.3 million in funds came from donations from British Columbians thanks to the Society's tireless campaigning. With these funds, they have been able to sign a memorandum of understanding with UBC and begin the recruitment process to hire a senior ALS Clinician Scientist to spearhead the project. They are eager to move into the second phase of *Project Hope*, which will require further funding to support the vital research, clinical trials, and clinical care that the Centre seeks to provide. The Society has committed to UBC that it will raise an additional \$20 million to support these initiatives.

UBC Professor Emeritus, Dr. Andrew Eisen, has provided figures to help understand some of the associated costs, saying "A single clinical trial for 40 patients costs \$1,460,000 (\$36,500 per patient) on average. The annual cost to operate a multi-disciplinary ALS clinic for 250 patients is \$1,662,500 and at any given time in BC there are over 400 people living with ALS, so the cost could be upwards of \$2,660,000 per annum." This demonstrates the need for substantive government funding contributions to adequately support Canadians with ALS living in BC.

The Society is also currently seeking funding from the BC government to reach this overall goal of \$20 million, with the support of the provincial Liberal party. I *urge you to follow suit* and join them in advocating for the funding that will allow this important project to start its work towards improving the lives of Canadians with ALS and finding a cure.

I look forward to hearing from you.

Sincerely,

A handwritten signature in black ink, appearing to read "Elizabeth May". The signature is fluid and cursive, with a long horizontal stroke at the end.

Elizabeth May, O.C.
Member of Parliament
Saanich-Gulf Islands
Parliamentary Leader of the Green Party of Canada



HOUSE OF COMMONS
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CANADA

Todd Doherty

Member of Parliament
Cariboo—Prince George

January 27th 2023

Hon. Jean-Yves Duclos
Minister of Health
House of Commons
Ottawa

Dear Minister Duclos,

I write this letter to express my strong support for a request for \$10 million in funding by the ALS Society of British Columbia, to support the second phase of their initiative – Project Hope.

In 2019, ALS BC set a commendable goal to establish an ALS Research Professorship at the University of British Columbia to be held by a clinician/scientist to champion and run the programme – Project Hope. This project aims to create a world class ALS Centre at UBC that will strive to create an optimal environment integrating research and clinical care.

ALS is a debilitating illness that becomes progressively worse within a very short time span once afflicted. It affects thousands of Canadians, with over 1,000 people dying from it every year.

Through my work as co-chair of the House of Commons ALS Caucus and through frequent interactions with the many ALS advocacy groups, such as ALS Canada, I have witnessed heart-breaking stories of Canadians living and dying with ALS and the impact upon their families.

While I had participated in ALS awareness campaigns like the ice bucket challenge before being elected, it wasn't until watching our former colleague Mauril Belanger's rapid deterioration during my first days as a Parliamentarian did I fully understand how devastating ALS was and I committed right then to do whatever I could to fight this terrible disease.

The most recent victim of this terrible disease is a constituent of mine and a Canadian Armed Forces veteran, Deane Gorsline, who passed away this month at the age of 33. During the four years after his diagnosis, not only did Deane pursue treatment options for himself but he felt compelled to contribute to creating an organization whose goal was to facilitate treatment options for all Canadians living with ALS. He founded ALS Action Canada and served the remainder of his young life fighting for treatment opportunities for ALS patients across Canada.

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Todd Doherty

Member of Parliament
Cariboo—Prince George

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As I told Deane many times, I remain steadfast in my commitment to helping Canadians already struggling with ALS and towards our collective search for a cure.

Therefore, Minister, please accept this letter as an expression of my fullest support for ALS Society of British Columbia's request for \$10M in funding for its Project Hope.

I'd be happy to answer any questions you may have about this funding request and about the ongoing advocacy on behalf of ALS patients across Canada. Thank you for your consideration.

Sincerely,

Todd Doherty, M.P.

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